

Pediatric Epilepsy – Creating an Epidemiologic Epilepsy Network in Sicily

10th July 2019

King's College London & University of Catania

Venue: “Aula 2 – Pad. 4” – University Hospital “Policlinico-Vittorio Emanuele”, Catania, Italy

08:30 – Authorities’ Greetings – University of Catania, Department of Clinical and Experimental Medicine, Section of Pediatrics and Child Neuropsychiatry.

Experiences in Epilepsy Epidemiology: From London to Catania

Presented by Martino Ruggieri and Deb K. Pal

09:00-09:15 – Eyelid Myoclonia with Absences: an under-recognized entity? An epidemiological experience – Loretta Giuliano, *Researcher, University of Catania*

09:15-09:30 – *BIOJUME*: A thesis study from London to Catania – Michela Leotta, *Medical Student, University of Catania*

Creating the Registry – 09:30 – 13:00

- Session 1.** Epilepsy in Sicily – What are the Important Questions?
What is a registry? Examples of registries for rare disorders
What are the purposes of an epilepsy registry?
- Natural history
 - Geographic variation in clinical practice
 - What treatments are in use and where
 - Comparison against, or develop, shared management guidelines, eg
 - time from 1st seizure to specialist care
 - Use of rescue medications
 - Use of appropriate investigations
 - Time to MRI
 - Referral to expert eg Drug Resistance, comorbidity, infants
 - Valproate in females
 - Genetic testing
 - Predictors of poor outcomes
 - Impact of quality improvement programmes
 - Metrics to track quality of patient care

Discussion – Do we need a Sicilian Epilepsy registry?

Discussion – can registry be enriched by linkage eg pharmacy, school, death?

Discussion - does accessible, high quality data already exist

- Session 2:** **Discussion** - who are the stakeholders?
Discussion – what questions to answer?
Discussion – Prioritising goals
Discussion – Ethical issues
Discussion – Feasibility
Funding and scope; building on available resources
Existing data elements and registry platforms

Session 3: Next steps towards funding

- Build the team – Scientific Advisory Board roles
- Governance and data access arrangements
 - Committee
 - Coordinator
 - Subject experts
 - IT staff
 - Ethics/legal
 - QA expertise
 - Biosamples
- Define the dataset, target population and patient outcomes
- Site selection
- Patient group engagement
- Institutional agreements
- Resource planning and budget
- Develop protocol
- Develop project plan

Organizing Committee

Prof. Deb K. Pal

Prof. Martino Ruggieri

Prof. Andrea Praticò